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ABSTRACT

This case study is based on a 1988 site visit to the Orion Community, in which a group of nondisabled and disabled people have chosen to live and work with each other in Chester County, Pennsylvania. Orion's founding is described, beginning with an informal support group of professionals, parents, advocates, and members of Camphill (agricultural villages that welcome individuals with developmental disabilities). The founding group sought to support people coming out of Pennhurst, a large state-operated institution for individuals with mental retardation and other disabilities; to build upon the presence of Camphill; to acknowledge the important contributions that people with developmental disabilities can make to the community; and to include a spiritual and religious foundation. The case study describes the households where the members live with each other, the Guild House where some Orion members and others work together, the encouragement of lifesharing, the offering of hospitality, decision making in the community, care groups, and compliance with state regulations. (JDD)

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Center on Human Policy

IN THE SHADOW OF PENNHURST:

THE ORION COMMUNITY

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IN THE SHADOW OF PENNHURST: THE ORION COMMUNITY

Zana Marie Lutfiyya
July 1990

This case study is about the Orion Community, a group of nondisabled and disabled people who have chosen to live and work with each other in Chester County, Pennsylvania. This report is based on a 5-day site visit on September 23-27, 1988, which included observations and interviews with several Orion members. The purpose of the visit was to learn more about positive practices in supporting people with developmental disabilities. It reflects Orion as it was only at the time of the visit, and not any changes which may have been made since that time. It should be noted that Orion is not a human service agency as there are no staff people, nor any paid caregivers.

West of Philadelphia, and off the Main Line, I found myself driving through rolling hills and small villages: Phoenixville, Kimberton, Spring City. Spring City boasts a three block stretch of a main street. When I came to the end of it and looked to my right, I saw the tall smokestack of a nuclear power plant releasing puffs of white smoke hundreds of feet up into the air.

Down on the ground, I drove up to a black fence with jagged and pointed pieces of stone stuck into the top of it. It is a low fence, only three feet high, and it follows the curve of the road. This fence is the outermost perimeter of Pennhurst. At one time, about 1,200 people with mental retardation and other disabilities were housed here. Many of the residents were neglected, abused, and even killed during their stay here. In 1984, the Commonwealth of Pennsylvania agreed to close Pennhurst by moving the residents into smaller homes in the community. In February 1988, the final two residents moved out and Pennhurst ceased being an institution for people with developmental disabilities.

The drive around the large campus reveals a quiet and peaceful place. It is hard to imagine the sheer number of people who lived and worked here, the beatings with toilet brushes, burnings of flesh with hot metal keys, the contractures of limbs acquired over many years of nonmovement. The place today is so quiet, and I see no one outside at all even though it is a warm sunny day and cars are parked here and there--the place feels so abandoned that it is hard to imagine that anyone had ever lived here at all. I pull up to the last group of brick buildings by the gate and read the new red and white signs: "Veterans Hospital. Building One." Another use has been found for Pennhurst.

Like the smokestack of the nuclear power plant, Pennhurst casts its shadow on the surrounding countryside. This shadow reaches back in time, for the presence of this institution and the plight of the men and women trapped inside helped to influence a small group of people to change the way they live their lives.

The History of Orion

It is difficult to trace the history of the Orion Community. Unlike formal agencies or programs that serve people with developmental disabilities, there are no formal policy guidelines documenting what it is. There is no admissions and discharge committee, no per diems and no "beds." In fact, members aren't quite sure of exactly how many people are "in" Orion: for membership is not based on either giving or receiving a residential service. For those interested in program administration, Orion is messy. The history of Orion is remembered orally and some of the founding members don't remember all of the details. For instance, no one I talked with remembered exactly how "Orion" was chosen as their name in the first place.

But people do remember that it was Helen Zipperlin[1] who came up with the name. Helen grew up in Scotland and emigrated to the USA with her husband Hubert in order to help found the Camphill Village on a gift of land at Kimberton Hills, PA.[2] Helen could not tell me why she chose the name of "Orion." But she did tell me how the Orion community began.

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[1]With the exception of Helen and Hubert Zipperlin and Lou Chapman, all of the names in this report are pseudonyms.

[2]Camphill is an international organization of agricultural villages. Camphill communities were originally set up to welcome refugee children after WWII, immigrants, and later, people with developmental disabilities, particularly mental retardation. Based on the principles of anthroposophy, as described by Rudolf Steiner, Camphill villages attempt to be self-sustaining.

> Pennhurst started to close. Many of us thought that Camphill would be the first step, the first stopping place for many of the people leaving the institution and coming into the community.

In the first days after the Pennhurst decision was handed down, Helen decided to become involved in the transition of the residents into the community. So she became involved in the local Association for Retarded Citizens (ARC), sitting on the Residential Services Committee. Through her participation on this committee, Helen met the others who eventually formed the core group of Orion. At the annual state ARC conference one year, Helen went to a session held by the religious division of the ARC.

> There was this sermon about how we should bring religion to the little ones in the institution. It wasn't very good. I couldn't hold back. [I said] that if anything, we were the little ones in need of religion, not the people left in Pennhurst. That caused quite a stir, and it started people talking.

The chaplain at Pennhurst got in touch with Helen and invited her to an information session that he was putting on about l'Arche[3]. Helen and several others were so inspired after hearing about l'Arche, that a group formed to pursue the possibility of starting a l'Arche community in Chester County for people coming out of Pennhurst. The l'Arche community in Erie, Pennsylvania, sent its founder and director, Sr. Barbara, down to meet with this group.

As Helen related,

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[3]l'Arche, founded by French Canadian Jean Vanier, is a series of intentional Christian communities around the world where people with and without developmental disabilities live together.

> Now I guess by this time, Orion had already started, though we may not have realized it. There were informal monthly meetings where we were trying to support each other. That was such a time! There was sheer joy and excitement and suffering together.

As it turned out, l'Arche was not able to start a household in Chester County. But Sr. Barbara encouraged the group nonetheless. Helen recalled,

> Sr. Barbara met everyone who would become Orion. She told us, "But my dears, why call it l'Arche? Just do it yourselves and I'll pray for you." And that is what we did.

And so, amidst the turmoil and excitement of the plans to close down Pennhurst, the Orion community was born.

The Founding Group of Orion

At the beginning, Orion was an informal support group of individuals: professionals, parents, advocates, and Camphill members who lived and worked in Chester County. During my visit I asked several people about who belonged to Orion. Interestingly, for such an informal organization, I found complete agreement on who the founding members were, including Helen, Steve, Lou, Bob, Nora, and Robert. Steve is a social worker at an institution (but not Pennhurst), while Bob is a parent with two disabled children who was referred to Helen for help. She invited him to the early meetings and he has been there ever since. Lou is also a parent of a daughter with disabilities. She was actually involved in the ARC movement, but was dissatisfied with what to her was the overprofessionalization of residential services. She moved from another state specifically to cofound and join Orion. Nora was

involved in local services for people with disabilities and in Orion in the early days, but recently illness limits her participation. Robert, a lawyer was also once part of the ARC movement. Although Nora and Robert are now not intimately a part of Orion's day to day life, both are consulted about major discussions facing the community.

Their initial purpose was to support people with developmental disabilities to live in the community with nondisabled individuals. The goal was to support households where such individuals could live together and share their lives. In addition, these households were to be part of the larger community in Chester County, and not self contained entities unto themselves. For Orion members, lifesharing was different from the traditional, community-based residential services that existed: group homes, supported apartments and so on. The difference they hoped would be found not so much in the physical structures of the household, but in the way life was lived within each household.

The core/founding group of Orion adopted the following beliefs as essential in shaping their efforts. The first was to support people coming out of Pennhurst. This was later expanded to supporting people with disabilities to lifeshare if they wanted to, regardless of where they had been living. Second, the members of Orion wanted to build upon the presence of Camphill. Camphill was and is a rural, self-sustaining village community. Orion members wanted to be associated with Camphill but also be integrated as part of the larger community in Chester County. Third, to acknowledge the important contributions that people with developmental disabilities could make to the lives of others in the community. The dissatisfaction with traditional residential services stemmed from the perception that people with

developmental disabilities were treated as beings to be cared for. Finally, the founders of Orion felt the need to engage in a lifestyle that included a spiritual and religious foundation.

In order to accomplish these goals, the founders of Orion decided to start a spiritually based intentional community that would support people with developmental disabilities to become a part of the local life of Chester County. People with and without disabilities would choose to live with each other and no one would be "placed." Orion would not charge for services: there would be no staff people, paid or voluntary. There would be no staff people at all. This community would not join the International l'Arche Federation, nor Camphill, but Orion members would maintain personal connections with members of each of these organizations. In fact, with Helen, there would be an overlap of membership. As she explained: "I believe that the future is in the noncontiguous community. The future is in making a place in the larger community as Orion tries to do."

She went on to say that part of the purpose of Camphill is to form a self-contained village. For her, Camphill is thus a "contiguous" community. By contrast, Orion strives to become a part of the larger world, and is dispersed into several households across Chester County.

ORION TODAY: MEMBERSHIP

The essence or heart of Orion is not to be found in the physical locations where the members live and work. It is to be found in the members themselves. The Orion Community is a group of people who by informal consensus and/or mutual acknowledgment see themselves as the constituent members. This group changes over

time as people move into or away from the community. Lou compared the membership of Orion to the layers of an onion. At the center is a core group of people. Others join the community, and depending on their closeness and attachment to the aims of Orion place themselves and are placed by the other members in the core or in the succeeding layers.

Describing Orion is not easy, because it isn't a single entity. One of the components of Orion are the households where the members live with each other. Another is the Guild House, where some Orion members and others work together. And then the Orion membership can be thought of in the following ways: first, as a network of individuals, second, a smaller group committed to living and/or working together as an intentional community, and third, it is a group which wishes to encourage others to lifeshare as well.

The Households

Almost all of the people who are seen and see themselves as members of Orion live in households with other members. A household does not have to have a person with a disability in order to qualify as an Orion household. Orion includes households with married couples, families, and single adults who have chosen to share their lives. Who lives with whom depends on the choice and preferences of everyone involved. It is difficult to get a specific number of "Orion households" or "members" because of the inclusionary definition of Orion's membership. As Lou explained, "We just don't talk about who is in or not in Orion. It's just not part of our life together. I can never answer how many people are in Orion."

There are levels of membership and involvement, but even the more peripheral households are considered part of the Orion community. Lou explained that there is a core group of Orion members, and then the successive layers of membership and involvement. She defines core group members as those who "carry the vision of Orion, or the potential vision of Orion." The core group are the founding members, as well as Laura and Kyle. With the exception of the latter two individuals, the core group has been together as such for ten years.

There do appear to be some core households as well. In these households, most if not all of the members see themselves as part of Orion, and have made a fairly extensive personal commitment to lifesharing. These include: Lou, Peter, and Frank; Kyle and Laura; Betty, Alison, and Cherry; Bob and Sandy; Gus, Anne, Ralph, and his son Tom. But the households do undergo a fair bit of change over the years. For instance, another married couple expecting their first child were moving in with Kyle and Laura while Betty was planning to relocate to another town. Although Betty had invited both Alison and Cherry to move with her, they had chosen not to.

Lou defined the next (or second) circle of people as "folks who have a strong role to play but are not so involved in the vision. They take part in various things, but not on a daily basis." For example, a young family with four children attend Orion gatherings and social events and are considered to be members, but are not invited in the day to day life of other members. Lou continues by describing the third circle of individuals who are involved in Orion: "There is a great big circle of people who support us financially, come to our celebrations and they support us in some way because they are interested."

Orion members live in households throughout Chester County. Some individuals in the third circle live across Pennsylvania, and in other states as well.

The Guild House

The Orion community is not confined to households where people have chosen to live with each other. They also operate the Guild House, a place where people come and work. The Guild House contains a woodworking shop, a weavery with half a dozen looms and two spinning machines, and an area where people make notecards and other stationery. There are a few offices on the second floor, and this is where Lou works. The mostly men in the woodworking area produce bookshelves and a variety of wooden toys for children. The women weave shawls, table cloths, and blankets. Some people work at a nearby flower farm and one woman goes horseback riding during the week. But most of the two dozen individuals spend their days here at the Guild House itself.

Not all of the people who work here are members of Orion. Several live in the nearby Camphill Village and a few live at home with their families. The workday here starts with a "circle time." Everyone gathers in the largest room to say grace, and have time for individual prayers. The circle time concludes with everyone reciting in unison two sentences written by Steiner. "The healthy social life is found in the mirror of each human soul the whole community finds its reflection. And when in the community the virtue of each one is living." Once a week everyone spends about an hour singing together to the accompaniment of two guitars. And at one lunchtime each week, one woman teaches everyone else the basics of American Sign Language.

No one who works at the Guild House receives a salary, although everyone takes some money home with them each week. These are called "enablements." Individuals are asked to request the amount of money that they need. This is an honour system...one is expected to take into account other sources of income. This might be from another paying job, a pension or other investments, or from Social Security. For many of the people with developmental disabilities, their Supplemental Security Income (SSI) payments pay for their room and board, and clothing. Their enablement requests are meant to cover social and recreational activities, vacations, and special trips. Some individuals without disabilities take home very little or no money as they have sufficient sources of income. The other limitation to the amount one receives is based on the earnings of the goods produced at the Guild House. The main money making events are the pre-Christmas craft sales in the Philadelphia area. The community still tries to raise money through individual donations every year.

But the point of the enablements is to recognize the contributions of all the people at the Guild without tying it to production. As Lou explained to me:

> Well, one does work to accomplish something. You really can't put a price on that. Philosophically, it is also important to look at what a person needs and what ideally would meet those needs. Its not the work but the needs that should determine what a person should get.

To illustrate this point, I was given the example of Erik. Until a few years ago, Erik was a skilled worker who had the highest production rate in the woodworking area. Then he suffered a severe stroke. After months of recovery, he can now take part in some of the tasks like sanding assembled products by hand, but his rate of production

is much less than it used to be. Helen and Lou emphasized that Erik still makes a valuable contribution to everyone else at the Guild through his presence, and reject the notion that he should no longer receive money that would make a big difference in his life. So he continues to receive his enablement and take part in the ways he can at the Guild House. Again, Lou asserted,

> We have workers whose ability to produce varies along a wide spectrum. It is wrong to tie money to that. Because they contribute in other ways. Erik's presence is an absolute light right in the middle of us. His light was always there. But his contribution to us now is different.

A Network of People

Orion is not tied to any facility or building. People join in because they are either interested in the aims of the group or they know a particular individual who is already a member. Knowledge about Orion seems largely passed through word-of-mouth, although they do have some literature for distribution. Among this network of people, individuals, or households set up their relationships and contacts. People keep in touch through a variety of ways including social events, informal visits, and meetings.

People may be recruited to join Orion. This is typically done by issuing a specific invitation to interested individuals. Laura and Kyle's introduction to the community exemplifies this approach. Laura got a job at an office where Lou used to work. She and her husband expressed an interest, were invited to some social events and then became involved with some individual members of Orion. They subsequently were asked to join the care group for Lou's household. At the time of

my visit, Laura and Kyle were preparing for another married couple to move into their house with them. Several people I spoke with now consider Kyle and Laura as core members of Orion.

Members of Orion consciously try to expand this network of involved individuals. They have planned parties and other social events for all Orion members and then invited those they think might be interested or share a similar interest with a member. Generally, these new people are family, friends, or acquaintances of someone who is already a part of Orion.

Once a person expresses a desire to become involved in the Orion community, members try to assist the person to define possible roles. One new member, a woman who had just moved from Philadelphia to Chester County, was invited to join the care group for Lou's household. In turn, she offered to invite Peter and Frank to her house to stay when Lou travelled. She then asked for some training in order to do this. The response she received assured her that she didn't need training, but a chance to get to know Frank and Peter better. Suggestions ranged from having her come over for dinner, sleep over as a guest when Lou was at home, and then stay once when Lou was out of town. She was encouraged to invite Peter and Frank to her house whenever she felt comfortable to do that.

Intentional Community

Orion is more than a loose network of individuals. The interest in encouraging individuals with and without disabilities to live with each other is one that has been expressed by people. Members have consciously decided to live out their beliefs in an intentional community.

An intentional community is a group of people who purposefully decide to share their lives with each other. The decision to do this is typically tied to an overarching ideology. Religious orders are examples of intentional communities. Sometimes such communities assume a particular way or form of lifesharing. Both l'Arche and Camphill are intentional communities where disabled and nondisabled people live together. L'Arche's ideological foundation are the Beatitudes (taken from Christ's Sermon on the Mount), while Camphill's is rooted in anthroposophy. Proponents of anthroposophy have advocated a renewal of society through communal living and the creation of therapeutic environments. In both of these communities, people with disabilities are placed (either by the state or their families) into the community. While l'Arche has a clearly defined hierarchy of authority and responsibility, Camphill members are called co-workers or villagers, a distinction based primarily on whether the person has a developmental disability or not.

The Orion Community is the intellectual and spiritual descendant of both l'Arche and Camphill. Orion members may live in Camphill (eg. Helen) or, more commonly, have extensive personal ties with Camphill villagers. Although Orion members haven't had as much personal contact with l'Arche communities, they see themselves as allies.

Orion tries not to have any hierarchy nor distinguish between members in any way. Orion has a board, and is incorporated as a not for profit organization. This was done solely to enable them to receive donations. The board does not meet as a board. Helen explained, "We are not to be a governing body that runs an agency." While Orion tries to avoid a hierarchical set up, it does in fact have some structure to it. The Guild House, for instance, has a coordinator who oversees the

bookkeeping and overall management of the activities there. But this position has rotated among different individuals. Care groups (see section on providing supports for a more detailed description) are established for each household.

Encouragement of Lifesharing

In addition to being an intentional community, at least some of the members of Orion hope to encourage others in the larger community to seriously think about lifesharing. Orion members would like other individuals to also share their lives with others. To this end, Orion members along with Camphill, have applied for and received money from Pennsylvania's Developmental Disabilities Planning Council (DDPC) to undertake a "lifesharing project." Just getting underway in the fall of 1988, this was seen as an effort to encourage the development and support of lifesharing situations involving people with and without disabilities. As Helen said,

> The job of mentally retarded people is to recommunitize humanity. And to do this, we can only go so far with special places for special people or special agencies. The whole community needs this care, not just the special people. Now this is awfully good in theory, that everyone has a special capacity. We need to learn to live this. There are some mighty prophets of the future.

LIVING TOGETHER

While one important component of Orion are the members--who they are, another key element is how they live together. Certain patterns of living together have evolved over the years within this intentional community. These are the offering

of hospitality, the decision making process that is used, and the way that members support each other.

Hospitality

The offering of hospitality is a key feature of the Orion community. It includes hospitality between members, across households, and also the welcoming of guests and visitors. The act of hospitality (eg. sharing a meal, a place to stay, open to others dropping in) is important for at least two reasons. First there is the act of welcoming itself, the open invitation to others. Second are the outcomes of such hospitality -- other individuals will learn more about Orion, lifesharing, and people with disabilities, and will have the opportunity to become involved in a personal relationship with some members.

The act of welcome. For Orion members the act of welcoming an individual is important in and of itself. The language of hospitality and welcome that is used in Orion illustrates their view of how people should be viewed and treated. Instead of being placed in a sheltered workshop, one woman who lives at Camphill received hospitality from Orion. As Helen explained to me, "The Guild House is a welcoming place for Linda and others to do crafts, meet people, and enjoy. They, Orion, make space for us there."

On another occasion, after inviting several people to her house for an overnight stay, Laura was asked by a woman who had spent many years in services for people with mental retardation and mental health difficulties if Laura had ever done respite. The following exchange occurred:

L: No, well, I mean, what exactly is respite?

A: Well, you know its people like you and Kyle taking care of people who need a place to stay for a while.

L: No. I guess we don't do that. Why do you ask?

A: No reason, I was just wondering what you did.

Of course, in the human service mind view, what Laura and Kyle did was to provide respite. Respite is a paid service, respite providers must be trained, licensed, and so on. Laura and Kyle opened up their home and offered hospitality.

Outcomes of hospitality. Members of Orion also hope that the hospitality they offer will serve as something larger than the act itself. They hope that people will appreciate the symbolic nature to the act of opening one's home and life in order to share these with others. As Lou explained to me:

> One thing we see as a role that Orion might play in the overall scheme is just simply to be here. The presence in the community in the wider sense. People can observe, and be welcomed. Observe people who have been devalued yet who have great gifts to bring to us. There is a struggle to build new forms of people living and working together with a new respect for each other.

The presence of hospitality, openness, and welcome assumes a symbolic significance for members of Orion as well. These characteristics are taken as indicators that "healthy" lifesharing is occurring. Members note with concern if a particular household is less inclined to have other people over. Again, as Lou said, "The element of hospitality, of welcoming people to our homes without it becoming intrusive, might be one way of getting people know what we do and how we do it."

Decision Making in the Orion Community

Another example of how life is lived at Orion is the decision making process that is used. The members of Orion aspire to have no hierarchy at all, but rather a joint, consensual decision making process. Because this is an intentional community dedicated to living according to God's will, community members pray together and submit certain decisions to a group discernment process of prayer. Members talk about being "called" or "led" to a specific course of action. One example of this decision making process at work revolved around the development of Lou's household.

When she initially moved to Pennsylvania, she lived as a "houseparent" in a group home that Orion had taken over, then called the Village House. Established by parents prior to the inception of Orion, it was modelled after the Camphill households that do have live in houseparents. The Village House was eventually closed and the individuals assisted to move into smaller, lifesharing situations. Lou herself was by then a member of the Orion board, and had bought her own house. "My house, from the moment I moved in, was used as a respite guest house for people. The first six months I had only two nights to myself.

A number of people came to stay, including visitors to Camphill. "Guests came for a rest. They had had an operation or something and needed a quiet place to stay...for a rest, a peaceful place." Lou's guests included both individuals with and without disabilities. She had to support this work, and got a job at the local Citizen Advocacy office in Phoenixville. Lou continued to welcome guests into her home for nine years. Then a man with a disability whom she knew suggested moving into her household on a permanent basis. By July 1987, Peter and Lou had

> ...formed a close friendship. When the family he was living with moved to Massachusetts, he could have gone with them, but Peter said that he wanted to stay and to specifically live with me. He articulated all this a week before they were to leave. There was a rapid series of meetings with Peter, me, and the family. It became obvious that he was being pushed...to move. I said that I would welcome Peter but that I needed the support of the community. They said that they would support me.

This asking of and commitment to support came about during a series of meetings where prayer and discussion took place. Lou is clear that Peter instigated the move to her home. During this process, she came to realize that she was being called to share her life with Peter, and to form a more stable household with him, and to accept far fewer guests and visitors.

This household expanded to include Frank about a year later. In his case, his mother approached Lou and asked if he could move in with her. Lou and other Orion members wondered if either Peter or Frank really wanted this change. As Lou explained,

> I thought that Peter would resist it and I wanted to make sure that this was where Frank wanted to live. Peter was open to the possibility, and excited about it. I spoke with Frank. He seemed positive but it was hard to tell...Frank and I knew each other for years and we had a good relationship. There was no negative element, but it was hard to know what he really feels.

All of the individuals to be directly affected in a major decision take part in the process which takes place over a number of meetings, conversations, and informal get-togethers.

Providing Support for Each Other: Care Groups

Another unique characteristic deemed essential by members of Orion are the care groups. Each household that is a part of the community has a care group. These small groups voluntarily undertake the support of each member of the household. The entire household is supported, not only the individuals with disabilities. The care groups are seen as so important to the functioning of the households that two requirements regarding care groups have been established. The first is that anyone who comes to Orion with an interest in learning more about lifesharing must be prepared to join a care group and form personal relationships with individuals in a household. People are invited to attend a few meetings with an established care group to see how things go, and if they wish to remain involved they make a commitment to that household. Second, each household in Orion must have a care group affiliated with them.

Care groups in conjunction with their household determine how they meet. Some groups have formal monthly meetings, while others may meet on a more ad hoc basis. Care group members are encouraged to spend time at the household with the people who live there. Whatever the process, Orion members agree that these visits must be more than a friendly visit. Care groups must be prepared to challenge the household when this is deemed necessary.

The first care group was established when Peter and Lou decided to share their lives by living together. As Lou said, "We needed support to do this. If we are inward looking, it won't work. So, for Peter and I to say yes to each other, we knew we would need a support group." Care group members are drawn from other Orion households, the nearby Camphill Village, and other individuals who are affiliated with

Orion in some way. Each care group decides how often they will meet and carry out their work. Typically, these groups meet once a month in the household. All members of the household are involved in these meetings except under the most unusual circumstances.

Lou told me that all of the care groups changed after their initial inception as: "Initially, [it was] a care group for the people who live in this house. Now it is a care group for all of us." That this is so was evidenced by what the care group for Lou's and Peter's household does when it meets. Everyone present takes turns to share significant events, struggles, and concerns that they may have. An effort is made to insure that everyone can contribute to the discussion. At one meeting, Peter told everyone about the advantages he has by being a member of Orion: having his own bedroom and bathroom, being able to shut his bedroom door, answering the telephone. It is quite difficult to understand Peter's speech, and after he had finished, Lou asked him if she could share what she understood he had said with the others. Peter nodded as she made his points. On occasion, he would stop her in order to clarify a point. Several members of the care group assumed this role of interpreting what Peter had said, taking time to check with him, making sure that they had in fact understood everything he was trying to get across.

The group then outlined an agenda with the issues they will discuss, and proceeded through these topics. For example, Frank's mother still buys his clothes for him, and pays all of his bills. She receives his SSI money, and Frank sends her the money he receives from the Guild House to her. Lou has been trying to help Frank ask for more control of his money, and then also help him set up a budget. This has proved difficult, for Frank must then pay Lou money for the rent, utility bills and so

on. The care group with Frank decided that he should exercise greater responsibility for his money, and to start with the money that he earns from the Guild House, and to ask his mother for his clothing money. Frank was also encouraged to ask whomever he wanted to help him with his money. At a care group meeting, Lou turned to Frank and said,

> It would be better off if you can work it out. Someone to help you with your own money rather than me. You see, for Peter, Helen helps him out with his money. They [meet] two times a year when there is a conversation with Helen and Peter about the oversight of his money. Peter now does everything else on his own.

A moving and interesting thing now happened. Frank agreed that he wanted someone to help him with his money, and he was asked who he wanted to help him. Frank sat and thought about it for several minutes. During that time there was silence, and people sat, waiting, yet comfortable that this was a question worth mulling over. At one point, Lou asked Frank if he wanted any help, or wanted to talk to someone in private. Frank shook his head no, saying that he was still thinking about it. People nod, and we continue waiting in silence.

Then, Frank looks at Laura and says, "Laura, can you help me?" At this, Laura's husband Kyle laughs heartily, saying something like she might be a better manager of someone else's money than her own. Laura replies that she would be happy to help Frank if he wants her to. Frank nods yes. Lou now tells Frank that keeping his own money would allow him to do other things, like buy his own clothes rather than relying on his mother for this task. Frank looks wary at this suggestion, and protests, "My problem is that I can't read." People in the circle nod and Lou

replies, "You can buy clothes without reading. This group is saying to you that you can learn how to do that." Laura then tells Frank that the two of them can call his mother together to let her know that Laura will be helping Frank.

The work of the care group extends past the monthly meetings. Members come to the household on a regular basis for visits, meals, coffee. Sometimes they must respond to a situation in a more formal manner. One summer, neighbours reported to Lou that one of the men in Orion was outside his house in the early morning, exposing himself--walking around naked. Lou met with the neighbours and assured them that their concern would be addressed. But then a trusted next door neighbour called with three additional incidents to report. The care group held an emergency meeting and talked at great length with this man about the implications of what had happened. He steadily denied doing this, followed by assurances that he would not repeat the actions. He was told that he could not leave the house without his clothes on. Lou and another care group member visited all of the neighbours who had seen this man and asked them to call her immediately if it happened again, and to tell the man that this was not appreciated behaviour in the neighbourhood. The one next door neighbour was asked to join the care group, and she did. The men in the care group decided to spend more time with the man in question so as to deepen their personal relationship with him, for although several explanations were thought possible, they wanted to learn from him directly what was going on. A couple of months went by without incident and then another neighbour spotted him again. To forestall further upset (a call to the police was threatened by one neighbour), members of the care group got a friend of this man to invite him to stay with her for a month.

As Lou said,

> First, we didn't know how much more the neighbourhood would tolerate. Secondly, we needed to be able to work with this man, and find out what's going on. He had always had a good relationship with this woman. He has stayed at her house off and on over the years as a guest. So he was invited to stay with her for a month.

This was the first and only time that an Orion care group met without members of the household. They decided to redouble their efforts to get to know this man better in order to learn why he was exposing himself. No one at Orion ever thought of asking this man to leave the community, of punishing him, or of restricting his freedom. Efforts were made through the context of personal relationships with this man to try to understand his perspective for these actions while also letting him know that the behaviour was unacceptable. Several months after this series of incidents, it was discovered that this man had been accused falsely, and that another man was in fact responsible. The Orion members responded by making an effort to support the man who had exposed himself, while trying to overcome their feelings of betrayal.

THE CHALLENGE FACING ORION: SAFEGUARDS

Like any other endeavour, the Orion community faces some serious challenges in its efforts to promote and support lifesharing between individuals with and without disabilities. This is the safeguarding of their own efforts while also meeting the Commonwealth of Pennsylvania's regulations.

Perhaps the largest challenge that Orion faces is the issue of safeguards. Orion members are quite concerned with the question of insuring a good quality of life for

all those who live or work within the community. They struggle with this issue and have tried to adopt certain practices that will enable them to review and reflect on their efforts. They are also willing to abide by laws that apply to everyone in the community (i.e., general health and safety codes) but are not convinced that they should follow the categorical laws enacted that restrict or regulate the lives of individuals with developmental disabilities. In addition, the Commonwealth of Pennsylvania has also determined that it should somehow be involved in making sure that the people with mental retardation who live in Orion are protected.

Pressures From the Department of Public Welfare

In addition to their own concerns about the need for safeguards, Orion has received some pressure from Pennsylvania's Department of Public Welfare (DPW) to comply with their licensing procedures and the sixty-four attendant regulations. A statute stipulates that any service, agency, or organization that provides care to people with mental retardation must be licensed. According to the current DPW interpretation, only families are exempt from these regulations. As one DPW staff person pointed out to Orion members:

> Our public welfare code says what gets regulated, [and] the statute has to do with providing care. Your literature says you provide care, and it is care whether it is reimbursed or not.

Camphill as well as Orion are faced with this requirement to obtain licensing (l'Arche is already licensed). In response, Orion and Camphill decided to join forces and negotiate with the DPW. They proposed a series of symposia where the issues of

safeguards in lifesharing situations could be discussed. Orion's position will be highlighted in this section.

Orion's Safeguards

Members of the Orion community agree that it makes sense to be concerned about what happens to their members. But they worry about the implications of licensing that focus on physical sites and formal programmatic efforts. They are also aware that people with developmental disabilities have come to great harm while living and working in "regulated" establishments.

As an example of the efficacy of monitoring and regulations, Helen describes the apartment of a woman with disabilities. This woman had lived at Camphill but wanted to live in a different place. So she was hooked up with a residential service provider in a nearby town. She now lives in a small two bedroom apartment with a roommate and her cat. After a recent visit, Helen noted that this woman's apartment was untidy, dirty, in poor repair and so on. Yet this woman has support staff and the agency is constantly monitored. Later on, Helen said, "We cannot safeguard a place, but we can safeguard people." For members of the Orion community, safeguarding an individual's life is an ongoing process.

Ideology. At the heart of safeguarding an individual who is vulnerable in some way, many Orion members believe is living with others. Further, the lifesharing must be based upon a clear set of higher-order values than are typically found in legislation or social policy. As one participant at the first safeguards symposium said in response to a concern by a DPW official that unnamed others might try to imitate lifesharing:

> The basic need is to find commitment from people who live out of a spiritual foundation. This is found in l'Arche, the Amish, the Mennonites, the Hutterites, and the Bruderhof.

Lou added the fact that no one gets paid a salary to live together at Orion. Although people do receive enablements, these are low and people generally have to work at jobs outside the community or contribute from the social security and other pensions in order to cover their living costs. She concluded,

> The likelihood of abuse is minimal, because who is willing to live under this arrangement? Only those who are called to do something higher. Nobody does it for the money. The reasons we do this stuff provides the checks and balances.

Internal and external reviews. The Orion community has two sets of safeguards, internal and external. The internal process is the care groups. The desire of Orion members is that the members of the care group will not only learn what daily life is like in the household, develop personal relationships with household members, and support them, but also be prepared to challenge and confront them when necessary. But Orion members acknowledge that something more than the care groups are needed. As Lou pointed out, "l'Arche does this, but we know that that does not always work out well. We need to balance both external and internal visits."

The external set of safeguards are what Lou and Helen eventually came to call peer reviews. That is, teams of individuals who themselves share their lives would visit a household or the entire community to review and reflect upon what has been taking place. The criteria for these reviews are still unclear, but the process must be consistent with the culture or way of life in the household or community. The peer

reviewers would be invited to spend some time living in the community as a guest in order to learn firsthand what life was like. The reviewers would have to do this while respecting the privacy of the people in the home. For, while monitors typically review the services where people are placed, to visit Orion or another lifesharing situation, visitors would be in people's own homes.

Personal choice. Finally, Orion members want to insure that everyone who joins and remains in the community does so because s/he has chosen to do so. For instance, Lou worried that Frank's mother wanted him in Orion more than Frank wanted to move in. Typically, individuals approach community members, as Peter did, expressing an interest in being a member. This sense of freely and voluntarily choosing to live in an intentional community with others serves as an additional safeguard: people are free to come and go. In response to the notion that Orion provides care as a human service does, Helen adamantly declares, "In lifesharing, the word 'care' cannot be used in the same ways as service providers use it. If you do that, then everything becomes ridiculous."

CONCLUSION

It would be easy to romanticize certain aspects of lifesharing. After all, everyone at Orion has made a conscious decision to join and remain as part of this community. But the other side of lifesharing is the constant day to day struggle that automatically comes with people living together. Individual preferences and eccentricities must be accommodated for and tolerated, while decision making can be torturous if there is not an early consensus. Despite these very real difficulties, many Orion members cannot envision living in anything but a lifesharing situation.

REFERENCES

Pennsylvania settles key suit on facilities for the retarded. (1984, July 15). The New York Times.

Pietzner, C. M. (1986). Village life: The Camphill communities. Salzburg, West Germany: Neugebauer Press.